

Key community issue: access to healthcare

Note: this document primarily applies to England, but has relevance for our work throughout the UK more broadly.

Background

Our community has a wide range of health needs, requiring multi-disciplinary care from a range of specialist and community services. While we recognise there is fantastic NHS care provided to people across the country, too many people with muscle wasting and weakening conditions still experience a 'postcode lottery' in the quality of care they receive.

Many public sector services are struggling with a lack of funding and resources. Along with rising care needs, these challenges are putting health services under increasing pressure. The government is putting more money into the NHS, but they realise that this problem will not be solved overnight with one budget.¹

Specialist neuromuscular services also face similar challenges. Our [Centre of Excellence \(CoE\) Awards](#) programme audits neuromuscular services and recognises the high-levels of clinical and research achievement services provide. Around the country, some people living with muscle wasting and weakening conditions have access to services which provide outstanding care, promote best practice and which have demonstrated their commitment to improving health and care for our community. But our findings also show inequities in accessing specialist centres, pressures in community services (such as wheelchair provision) and areas for improvement in wide-ranging aspects of care.

We believe all people living with a condition should be able to access high-quality care no matter where they live in the UK. Our last *Community Survey* found 'Access to healthcare' was the second key policy priority area that mattered the most. Specifically, our community wants more timely and equitable access to healthcare.² This starts with investing in staff, facilities and other aspects of care to improve the availability and quality of neuromuscular care in the UK. This will help increase access to the long-term, multidisciplinary healthcare and support which people living with muscle wasting and weakening conditions rely on each day to feel good, both mentally and physically.

¹ The Guardian, "[NHS will not be fixed in single budget, says Wes Streeting](#)", October 2024.

² Muscular Dystrophy UK, "[Community survey findings](#)", May 2024.

What are the challenges?

1. The current state of neuromuscular services

We have been conducting a triannual CoE audit for 12 years to assess neuromuscular centres across the UK. This audit is used to promote best practice locally and nationally and acknowledge centres who provide outstanding levels of specialist neuromuscular services. The data gathered is critical to improving quality and outcomes for people living with neuromuscular conditions, as well as providing national benchmarking. It is also an opportunity for people living with conditions, and the wider community, to provide feedback about services to help bring about positive change.

Our latest audit was in 2023. 27 centres participated, of which 16 received the highest designation (centres that demonstrate with evidence how they meet most of the audit criteria).^{3, 4}

The following features were recognised across many centres as good practice:

- Active contributions to clinical networks provide the opportunity for NHS neuromuscular centres to engage with others, sharing best practice, challenges, and the opportunity for NHS staff to stay up to date with the latest information around neuromuscular care.
- It is important for NHS neuromuscular centres to ensure patients are supported to access the mobility and assistive technology equipment they need to live as independently as possible.
- The accessibility of centres is a highly important aspect of neuromuscular services; people with neuromuscular conditions require facilities that are fully accessible, well maintained, and complete with clinical equipment that can support patient care.
- A commitment to partnering with us (and other patient organisations), demonstrating the participating centres' commitment to working with patient organisations to improve neuromuscular care.

The following were recognised across many centres as areas of improvement:

- Promptly addressing and funding variations in access to a range of healthcare professionals, including allied health professionals.
- Respite care provision remains a scarcity, despite it being critical to improving quality of life for people with neuromuscular conditions, their carers and families.

³ The award categories, in descending order, are: NHS neuromuscular centres awarded a Centre of Excellence with Research status; NHS neuromuscular centres awarded a Centre of Excellence status; NHS neuromuscular centres awarded a Centre Pursuing Excellence with Research status; NHS neuromuscular centres awarded a Centre Pursuing Excellence status.

⁴ Muscular Dystrophy UK, "[Centre of Excellence audit report 2023/4](#)".

- Some NHS neuromuscular centres work in isolation in providing neuromuscular care and not collaboratively with other organisations within the local healthcare system.
- Another key aspect of improvement is how NHS neuromuscular centres can improve patient experience through the availability and frequency of routine feedback from their patients, their families and carers.
- People living with neuromuscular conditions may require rehabilitation management, including neurorehabilitation, to maintain or enhance their function and mobility. While centres may not provide these onsite, they need to make sure effective referral pathways are in place to ensure patients are seen at suitable facilities.

Previous research that we have carried out has also shown how funding concerns are hampering service development. Our *Setting the Standard Audit* (2016) found that one third of neuromuscular services have concerns around on-going long-term funding restrictions within the NHS.⁵ Despite seeing clear cases for how important these roles are, many trusts and commissioners still only provide temporary funding. This short-term funding makes long-term planning and service development significantly difficult for neuromuscular services. If these posts were lost without suitable replacements, this could also result in our community being missed and receiving incomplete care. We believe that it's unfair to patients who have muscle wasting and weakening conditions to provide a service for a limited period of time, when it should instead be long-term.

2. NHS workforce capacity

Neuromuscular patients require care from multi-disciplinary teams (MDTs), covering a range of specialists and community services. A core MDT for someone with a neuromuscular condition should include a consultant (e.g. a consultant neurologist), specialist neuromuscular physiotherapist, neuromuscular care advisor/clinical nurse specialist, and an occupational therapist. Some non-core roles that are also beneficial for people with muscle wasting and weakening conditions include clinical psychologists, dieticians, speech and language therapists and orthotists.⁶

Limited NHS workforce capacity, particularly within specialist departments, is not unusual in health and care services. Neuromuscular MDTs are also missing core and non-core health professionals to support those with muscle wasting and weakening conditions. This varies depending on where people live and has led to many people with muscle wasting and weakening conditions to experience a postcode lottery in care.

⁵ Muscular Dystrophy UK, "[Setting the standard: The current state of neuromuscular services and clinical trial provision in the UK](#)", April 2016.

⁶ Muscular Dystrophy UK, "[Centre of Excellence audit report 2023/4](#)".

Looking in more detail at some roles:

- **Neurologists:** The Neurological Alliance for England published 2022 survey data showing that 181,967 people were waiting for a neurology appointment, of which 3% had been waiting for more than a year.⁷
- **Care advisors:** Neuromuscular care advisors provide practical, social, and emotional support for people affected by neuromuscular conditions through regular clinics, home visits, liaison with other health and social care professionals. They play an essential role in reducing unplanned hospital admissions and in improving overall quality of life for patients in line with NICE guidance. There are only approximately 40 NHS-funded neuromuscular care advisors across the UK. Without access to these roles, people with neuromuscular conditions may experience less coordinated care and reduced quality of life. Lack of care advisors in certain regions also risks exacerbating health inequalities.
- **Mental health support:** Our All Party Parliamentary Group report *Access to psychological support for people with neuromuscular conditions* (2018) found that many with muscle wasting and weakening conditions have not been able to access psychological support for years.⁸ Without psychological support, our community don't have an avenue to discuss what impact living with a rare condition has on their mental wellbeing.

All these and other workforce challenges in specialist teams can result in longer waiting times for patients and poor care management.

What we're calling for and what we're doing

To reduce the postcode lottery in healthcare, we're calling for people living with a muscle wasting and weakening condition to get faster, better and more equitable access to NHS services and treatments. We'll also seek out opportunities to raise our priorities in the UK Government's new 10 year health plan and refreshed long-term NHS workforce plan.

We're calling for:

- The Government to create a sustainable funding settlement for the NHS, to ensure it's appropriately resourced to deliver specialist health services.
- The Government should also better support NHS staff, including by expanding the workforce and addressing shortages in key specialisms, such as neuromuscular care advisors.

⁷ The Neurological Alliance, "[Together for the 1 in 6: England findings from My Neuro Survey](#)".

⁸ All Party Parliamentary Group for Muscular Dystrophy UK, "[Access to psychological support for people with neuromuscular conditions](#)", November 2018.

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- Health commissioners and system leaders to adopt the principles of the newly published 'Optimal clinical pathway for adults with Neuromuscular Disorders'.⁹ This will help improve the quality of neuromuscular services and thereby raise health outcomes.

Although the broader system needs investment, we're already [working to identify and address](#) some of these root causes.¹⁰

- Our CoE awards recognise neuromuscular centres that provide outstanding care and promote best practice locally and nationally. [Find out more](#).
- We are part of 10 neuromuscular networks, of which we run five, to identify gaps, improve service quality and outcomes, as well as upskill health professionals. These networks bring together NHS commissioners, people with a muscle wasting and weakening condition, neuromuscular clinicians, and allied health professionals. [Find out more](#).
- We engage with commissioners and other relevant stakeholders to represent our community's interests and support service development. As part of this work, we support the submission of business cases to improve provision of neuromuscular care. This helps to influence decision makers to secure resources that are needed to enhance high-quality neuromuscular services, as well as bring benefits to service users, their families and carers. We also provide letters of support to accompany business cases developed by neuromuscular services.

As part of our wider work to improve healthcare for people living with muscle wasting and weakening conditions:

- After more timely and equitable access, our community told us their next big priority was 'ensuring patient voices are heard at all levels of the healthcare system'.¹¹ We work with health professionals, politicians and NHS decision makers, to raise the voices of people living with muscle wasting and weakening conditions. We also collaborate with other sector organisations and coalitions when we feel our community's interests could be served by joining wider health and disability calls to action.
- The third community priority was 'streamlining the process for treatment approval to make it faster/more efficient'. We work on ensuring the voice of people with a muscle wasting and weakening condition is taken into account by regulators when considering new treatments our community may benefit from. [Find out more](#) about how we do this.
- Although social care is not within the scope of this statement, we recognise the vital role it plays in supporting our community to live independently. We're a member of the [Care &](#)

⁹ The Neurological Alliance, "[Published: new optimal clinical pathway for neuromuscular conditions](#)", September 2024.

¹⁰ Muscular Dystrophy UK, "[Our Campaigning Work](#)".

¹¹ Muscular Dystrophy UK, "[Community survey findings](#)", May 2024.

[Support Alliance](#) (CSA). As part of the CSA, we're calling for the government to decisively address workforce, funding and other long-standing issues in the sector.

Any questions about this statement or our campaigning work, email campaigns@musculardystrophyuk.org.

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